Complete Summary

GUIDELINE TITLE

Occupational therapy practice guidelines for adults with neurodegenerative diseases.

BIBLIOGRAPHIC SOURCE(S)

Forwell S. Occupational therapy practice guidelines for adults with neurodegenerative diseases. Bethesda (MD): American Occupational Therapy Association (AOTA); 2006. 75 p. [138 references]

GUIDELINE STATUS

This is the current version of the guideline.

COMPLETE SUMMARY CONTENT

SCOPE

DISEASE/CONDITION(S)

Neurodegenerative diseases including:

- Multiple sclerosis
- Amyotrophic lateral sclerosis (ALS)
- Parkinson's disease
- Transverse myelitis

Note: *Neurodegenerative diseases* refers to conditions whose pathology results in a degenerative process to a part or all of the central nervous system (CNS). As the word *neurodegenerative* implies, the CNS degenerates over time, resulting in a progressive deterioration of client factors (body functions and body structures) and a subsequent decline in performance skills (motor, process, communication).

GUIDELINE CATEGORY

Evaluation
Management
Prevention
Rehabilitation
Treatment

CLINICAL SPECIALTY

Family Practice
Internal Medicine
Neurology
Physical Medicine and Rehabilitation
Preventive Medicine
Rheumatology

INTENDED USERS

Allied Health Personnel
Health Plans
Hospitals
Managed Care Organizations
Nurses
Occupational Therapists
Physical Therapists
Physician Assistants
Physicians
Speech-Language Pathologists
Utilization Management

GUIDELINE OBJECTIVE(S)

- To help occupational therapists and occupational therapy assistants, as well as those who manage, reimburse, or set policy regarding occupational therapy services, understand the contribution of occupational therapy for people with neurodegenerative diseases
- To serve as a reference for health care facility managers, health care regulators, third-party payers, and managed care organizations

TARGET POPULATION

Adults with neurodegenerative diseases, including multiple sclerosis, amyotrophic lateral sclerosis (ALS), Parkinson's disease, and transverse myelitis

INTERVENTIONS AND PRACTICES CONSIDERED

1. Referral for occupational services
2. Evaluation
    - Developing the occupational profile

    - Analysis of occupational performance through observation and assessment
3. Intervention process
    - Developing an intervention plan
    - Intervention implementation through establishing (remediation/restoration), maintaining, modifying (compensation/adaptation), and preventing deterioration of occupational performance
    - Intervention review
4. Outcomes assessment
5. Discharge
6. Follow-up

MAJOR OUTCOMES CONSIDERED

- Occupational performance
- Physical and psychosocial functioning
- Role competence
- Adaptation
- Health and wellness
- Prevention
- Quality of life
- Client satisfaction
- Length of stay in inpatient rehabilitation
- Rate of hospital readmission

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Hand-searches of Published Literature (Secondary Sources)
Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

The evidence-based reviews incorporated into this Practice Guideline consist of a review and ranking of the literature relevant to occupational therapy interventions published between 1985 and 1998. In addition, a follow-up search of the literature published between 1998 and 2002 was conducted using the same criteria of the earlier search.

Reviewers first identified key words and then searched the literature for articles to evaluate for review. They searched the following sources:

- Bibliographic databases (e.g., MEDLINE, CINAHL, EMBASE, PsycINFO)
- Consolidated information sources (e.g., evidence-based medicine reviews that include Database of Systematic Reviews, Cochrane Controlled Trials Register, and DARE—the Database of Abstracts of Reviews of Effectiveness).

Reviewers also scanned the bibliographies of selected key articles. After the literature search, reviewers then evaluated the quality of studies and ranked them using the evidence-based standards described in the "Levels of Evidence for Occupational Therapy Outcomes Research" (see "Rating Scheme for the Strength of the Evidence" in this summary). The appendixes in the original guideline document list the studies identified by the literature search.

Specific inclusion criteria for the evidence-based review conducted for this guideline were as follows:

- The article addressed the condition of interest (multiple sclerosis, transverse myelitis, amyotrophic lateral sclerosis, Parkinson's disease).
- Articles that included several neurological diagnoses were considered only if the condition of interest was a large portion of the study sample.
- The article described an intervention within the scope of occupational therapy practice, although it did not have to be a common occupational therapy intervention or administered by an occupational therapist or occupational therapy assistant.
- The study examined activity and participation levels of performance.

NUMBER OF SOURCE DOCUMENTS

Forty-seven articles were identified from online databases and bibliographies, except for 5 articles that included a pretest–posttest design (with or without a controlled group or randomization).

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Weighting According to a Rating Scheme (Scheme Given)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Levels of Evidence for Occupational Therapy Outcomes Research

Levels of Evidence	Definition
Level I	Systematic reviews, meta-analyses, and randomized, controlled trials
Level II	Two groups, nonrandomized studies (e.g., cohort, case control)
Level III	One group, nonrandomized (e.g., before–after, pretest and posttest)
Level IV	Descriptive studies that include analysis of outcomes (e.g., single-subject design, case series)
Level V	Case reports and expert opinions, which include narrative literature reviews and consensus statements

Note: Based on Sacket, D. L. (1986). *Rules of evidence and clinical recommendations on use of antithrombotic agents*. Chest, 89(Suppl. 2), 2S–3S.

METHODS USED TO ANALYZE THE EVIDENCE

Review of Published Meta-Analyses
Systematic Review with Evidence Tables

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Reviewers evaluated research studies published in peer-reviewed scientific literature according to their quality (scientific rigor and lack of bias) and levels of evidence.

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

Not stated

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

Not stated

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Not applicable

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

Referral

A referral for occupational therapy services for adults with neurodegenerative diseases is appropriate when a person experiences performance limitations in areas of occupation, such as activities of daily living (ADLs), instrumental activities of daily living (IADLs), leisure, and social participation, as well as in

work, education, and other productive activities. A referral to occupational therapy is also appropriate when an individual is unsafe performing occupations that may decrease independence or is faced with performance contexts that restrict participation. The sources of referral to occupational therapy services include, but are not limited to, the individual with neurodegenerative disease; family members or caregivers; employers; third-party payers; and health care providers, including occupational therapists, physical therapists, social workers, physicians, psychologists, and nurses.

Evaluation Process

Occupational therapists perform evaluations in collaboration with the client and target information specific to the desired outcomes. The two elements of the occupational therapy evaluation are (1) the occupational profile and (2) the analysis of occupational performance.

Occupational Profile

The purpose of the occupational profile is to determine who the clients are, identify their needs or concerns, and ascertain how these concerns affect engagement in occupational performance. Information may be gathered informally or formally and may be collected during one or more sessions. Developing the occupational profile involves the following steps as described in the *Framework* (see "Availability of Companion Documents" field):

- *Identify the client or clients*. Although the adult with neurodegenerative disease is the client in occupational therapy, the importance of the concerns and observations of caregivers and family members need to be considered during the evaluation process.
- *Determine why the client is seeking services*. Through interviews or checklists, the occupational therapist assists the client in identifying the current concerns relative to the areas of occupation and performance. What does the client hope will happen as a result of occupational therapy services?
- *Identify the areas of occupation that are successful and the areas that are causing problems*. On the basis of the client's current concerns, the occupational therapist identifies, with the client, possible supports and barriers related to occupational performance.
- *Identify the contexts that are supporting and inhibiting engagement in occupations*. Occupational therapists acknowledge the influence of contextual factors on occupations and activities. Factors that support or inhibit performance should be identified during the evaluation process.
- *Discuss significant aspects of the client's occupational history*. Life experiences (e.g., medical interventions, schools attended, prevocational experiences), interests, and previous patterns of engagement in occupations provide meaning to the client's life. These experiences may shape how the person deals with everyday routines and activities; and, therefore, the need for the occupational therapist to be familiar with the client's occupational history.
- *Determine the client's priorities and desired outcomes*. Before intervention occurs, it is important that the therapist and the client discuss and prioritize goals so that the therapist's evaluation and intervention will match the client's

desired outcomes. At this time, the therapist may need to refer the client to additional professionals to achieve these desired outcomes.

Analysis of Occupational Performance

Information from the occupational profile is used to focus the occupational therapist on the specific areas of occupation and the context to be addressed. The following steps from the *Framework* (see the "Availability of Companion Documents" field) are generally included in analyzing occupational performance:

- Observe the client performing the occupations in the natural or least-restrictive environment (when possible), and note the effectiveness of the client's performance skills (e.g., motor, process, communication, interaction) and performance patterns (e.g., habits, routines, roles), as well as the activity demands (e.g., objects, space, social demands, sequencing, required actions, underlying body functions and body structures needed to carry out the activity).
- Select specific assessments and methods that will identify and measure the factors related to the specific aspects of the domain that may be influencing the client's performance (see Table 1 in the original guideline document for a selected summary).
- Interpret the assessment data to identify what supports or hinders performance.
- Develop or refine a hypothesis regarding the client's performance.
- Develop goals in collaboration with the client that address the client's desired outcomes.
- Identify potential intervention approaches, guided by best practice and the evidence, and discuss them with the client.
- Document the evaluation process and communicate the results to the appropriate team members, referral sources, and payers.

This phase of the evaluation process comprises skilled observation of performance of occupations and activities that are important and meaningful to the client. It includes standardized and nonstandardized assessments in areas of occupation, performance skills, and performance patterns as well as activity demands, client factors, and context. Analysis of occupational performance will vary depending on the client's unique situation. There may be situations in which the occupational therapist may choose to evaluate client factors before observing occupational performance to gain insight into facilitators of and barriers to performance.

Areas of Occupation

Adults with neurodegenerative diseases frequently experience occupational performance issues in one or more areas of occupation. Table 1 in the original guideline document summarizes relevant problem areas typical of people with neurodegenerative diseases and provides examples of assessments used in the occupational therapy evaluation process.

Occupational performance issues may vary depending on the specific neurodegenerative disease. Evaluation often begins with the assessment of occupations of daily living that are basic, routine, and simple for the healthy adult but can be devastating for adults with neurodegenerative diseases. The

occupational therapist also needs to address occupational performance areas of work, education, and leisure, as they often provide the incentive for the client to optimize competence in ADLs and IADLs.

Performance Skills and Patterns

The careful assessment of daily occupations for people with neurodegenerative disease also includes identifying subtle factors that may affect performance. *Performance skills*, the observable elements of action of an occupation, can be subdivided into *motor skills*, *process skills*, and *communication skills*. Although difficulties with certain performance skills, such as mobility or strength, may be observed at the start of the evaluation process, deficits in others may be more subtle and may be masked or invisible until the client is attempting to carry out an activity over time. Examples may include disorganization as the activity progresses, inability to attend to the activity over time, and fatigue due to reduced endurance.

In addition, occupational therapists and occupational therapy assistants need to recognize that patterns of performance can also support or inhibit daily life activities. Although some of the roles, habits, and routines an individual developed before the onset of a neurodegenerative condition may help in the participation of daily activities, others may need to be re-evaluated.

Client Factors

There may be times, depending on the complexity and severity of the disabling condition, when client factors are assessed in greater depth. The sensitivity and honed clinical judgment of the clinician are necessary to complete an assessment that builds on successes and is meaningful for the individual.

Activity Demands

Determining whether a client may be able to complete an activity not only depends on the performance skills and performance patterns of the individual but also whether the demands of the activity itself place constraints on the person's ability to successfully participate in his or her desired occupation. During the evaluation, the occupational therapist needs to determine whether participation in an occupation is limited by the performance skills and performance patterns of the individual, the demands of the activity, or a combination of both.

Context

Occupational therapy practitioners appreciate that the contexts in which an individual participates greatly influence success and satisfaction in carrying out valued occupations. As such, occupational therapists formally and informally assess the influence of the context or the interrelated conditions (cultural, physical, social, spiritual, temporal, and virtual) within and surrounding the client that influence performance.

Setting/System for Service Delivery

Settings and systems in which people with neurodegenerative disease receive services are aspects of the physical context that influence the occupational therapy intervention plan. In an acute care hospital, the client is ill and medically unstable, and performance skills may be functionally compromised. The focus of therapy tends to be on self-care activities that are important to the client (individual), functional mobility, and the performance skills or client factors necessary to perform desired occupations. In a rehabilitation center, clients are medically stable and are more able to focus on all areas of occupation, related performance skills, and performance patterns necessary for returning to home and work. In an outpatient, community-based, or home-care setting, the intervention plan focuses on maintaining and supporting occupational performance in a safe and satisfying way while preventing deterioration. The Table below provides an overview of the typical intensity, frequency, and duration of occupational therapy services for people with neurodegenerative diseases within various health care and related settings.

Table: Intensity, Frequency, and Duration of Occupational Therapy Services for People with Neurodegenerative Diseases in Various Health Care and Related Settings

Setting	Typical Focus of Intervention	Typical Intensity, Frequency, and Duration of Occupational Therapy Services
Inpatient		
Acute care hospital	Improving performance skills related to activities of daily living (ADLs), mobility, and cognition.	Treatment provided 15–60 min/day, 5–7 days/week. Duration varies with medical stability.
Rehabilitation center	Improving competence and independence in occupations necessary for discharge to home.	Treatment provided for at least 90 min/day, 5–7 days/week. Duration of treatment depends on client's progress but typically ranges 1–3 weeks.
Subacute center	Improving competence and independence in activities and occupations necessary for discharge to home.	Treatment provided 30–90 min/day, 5–6 days/week. Duration typically ranges 1–3 months.
Nursing facility	Optimizing occupational performance in the face of physical and/or cognitive deterioration.	Treatment provided 30-90 min/day, 3–5 days/week. Duration typically ranges 2–5 months.
Outpatient	Improving competence and independence in occupations related to home, including ADL, instrumental ADL, work, leisure, education, and social	Treatment provided 30–60 min/day, 1–3 days/week. Duration will vary.

Setting	Typical Focus of Intervention	Typical Intensity, Frequency, and Duration of Occupational Therapy Services
	participation.	
Home Health	Improving competence and independence in occupations related to home or community.	1–3 visits/week. Duration typically ranges 1–2 months.

Intervention Process

The intervention process, which is based on the findings from the evaluation, is divided into three stages: (1) intervention plan, (2) intervention implementation, and (3) intervention review.

Intervention Plan

As a part of the occupational therapy process, the occupational therapist develops an intervention plan that documents the client's goals within an occupational framework, the planned intervention approaches, and recommendations or referrals to others. The intervention plan outlines and guides the therapist's actions and is based on selected theories and frames of reference and the best available evidence to meet the identified outcomes. The intervention plan is a collaboration among the occupational therapist; occupational therapy assistant; client, spouse, family, and others, as appropriate.

The goals and priorities of the intervention plan are established through a collaborative process and are based on the client's desired outcomes. At times, the goals of the client with neurodegenerative disease may not be realistic, may be ill advised given the current stage and degenerative nature of the disease, may have unsafe ramifications, or may place people at risk for injury or illness. Unrealistic goals may be due to lack of insight, decreased awareness, and inability to accept the stage or debilitating nature of the disease. Occupational therapists provide the client with graded decision-making choices within the scope of occupational therapy services and safety parameters and advocate for the client while respecting the client's decisions and wishes.

Depending on the disparity between goals and level of disability, the occupational therapist can assist the client in optimal decision making by:

- Providing education on the skills, resources, and contexts required to achieve the goals
- Identifying and educating the client about the potential risks or consequences of decisions
- Indicating whether goals are realistic at this time
- Developing client goals that are achievable
- Developing a prioritized plan for achieving client goals
- Establishing a graded therapeutic program (with timelines) to work toward specific goals

Intervention Implementation

The second stage of the intervention process is implementation of the intervention. Occupational therapists and occupational therapy assistants use several approaches to enable clients to meet their goals. These approaches, typically used in combination, include the following:

- *Create or promote* occupational performance
- *Establish or restore* occupational performance
- *Maintain* occupational performance
- *Modify* occupational performance
- *Prevent* deterioration of occupational performance

It should be noted that the first approach (create or promote) is not applicable for use with people with neurodegenerative diseases, as this health promotion approach assumes that disability is not present. The four remaining approaches, however, offer adults with neurodegenerative diseases a variety of therapeutic strategies. The Table below provides examples of occupational therapy intervention under the rubric of these four approaches. The type of interventions selected are based on determining the most effective intervention plan for a given client. The types of interventions include, but are not limited to, therapeutic use of self; therapeutic use of occupations and activities that encompass occupation-based activity, purposeful activity, and preparatory methods; consultation; and education process.

Table: Occupational Therapy Intervention Approaches

Approach	Focus of Intervention	Examples of Occupation-Based Goals*
Establish, restore (remediation, restoration) — an intervention approach designed to change client variables to establish a skill or ability that has not yet developed or to restore a skill or ability that has been impaired*	Performance skills	Improve grip strength and coordination by providing a hand exercise program to perform ADLs and IADLs.
	Client factors	Improve information-processing abilities through computer-assisted cognitive retraining.
Maintain — an intervention approach designed to provide the supports that will allow clients to preserve their performance capabilities that they have regained, that continue to meet their occupational needs, or both	Performance patterns	Maintain an appropriate medication schedule by using a checklist and timer.
	Context	Maintain safe and independent access by

Approach	Focus of Intervention	Examples of Occupation-Based Goals*
		reorganizing locations of key items stored in the kitchen.
	Client factors	Prevent loss of range of motion by providing hand and foot drop splints to maintain independence with child care activities within and outside the home.
Modify (compensation, adaptation) — an intervention approach directed at "finding ways to revise the current context or activity demands to support performance in the natural setting... [includes] compensatory techniques, including enhancing some features to provide cues, or reducing other features to reduce distractibility"*	Performance skills	Achieve optimal sitting posture through wheelchair modifications.
	Performance patterns	Establish a morning routine that incorporates newly learned energy conservation techniques.
	Activity demands	Improve independence in self-feeding by providing adaptive equipment such as weighted utensils.
	Context	Achieve access to home through installation of a ramp and stair glide.
Prevent (disability prevention) — an intervention approach designed to address clients with or without a disability who are at risk for occupational performance problems**	Activity demands	Prevent caregiver and/or client injury by instructing in work simplification and energy conservation techniques.
	Context	Prevent social isolation by suggesting participation in support group, day program, respite care.

Note: From "Occupational Therapy Practice Framework: Domain and Process," by American Occupational Therapy Association, 2002. *American Journal of Occupational Therapy.* 56, p. 627.

*In practice, these goals would also incorporate individualized measurement and time frames.

**Source: Dunn, W., McClain, L. H., Brown, C., & Youngstrom, M. J. (1998). The ecology of human performance. In M. E. Neistadt & E. B. Crepeau (Eds.), *Willard and Spackman's occupational therapy* (9th ed., p. 525–35). Philadelphia: Lippincott Williams & Wilkins

Although all types of occupational therapy interventions can be used for all approaches, the therapeutic use of self is an overarching concept that should be considered in each therapeutic interaction. Therapeutic use of self is a vital responsibility of the occupational therapy practitioner. Perhaps the fundamental attribute required is the ability (and taking the time) to listen to and understand the gravity of concerns. There are numerous types of support desired at any stage of the disease process. The areas that most often require support for people with multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), Parkinson's disease (PD), and transverse myelitis (TM) and their significant others are providing the right amount of information, clarifying misconceptions, coping with and managing the degenerative changes and potential changes, assisting with premature role changes, and coping with changing personal and family financial circumstances. In the final stages of the neurodegenerative disease, support may be required for coping with end-of-life issues. The description that follows sets out examples within these approaches and types of occupational therapy intervention for adults with neurodegenerative disease.

Establish or Restore Occupational Performance

This approach attempts to restore or remediate performance that approximates levels achieved before the onset of the disease or deterioration. Given the progressive nature of the condition and the difficulty with transferring skills from one situation to another, this approach is not frequently used by occupational therapists and occupational therapy assistants working with clients with neurodegenerative disease.

Maintain Occupational Performance

This approach is used in occupational therapy intervention to provide supports that will allow clients to preserve their performance capabilities and prevent any acceleration in deterioration of function. This is often achieved through provision of equipment, orthotics and splints, and education in energy conservation techniques.

Equipment. As a result of the progressive nature of neurodegenerative disease, equipment that assists in maintaining function is readily used and is frequently a component of occupational therapy intervention. The number of items and complexity of equipment increases with advanced stages of disease. (See the original guideline document for examples of typical equipment considered.) Although some clients may be able to use adaptive equipment as purchased from a distributor, others may require therapeutic intervention to be able to engage in their daily activities with a device. For example, a client may require fine motor coordination and dexterity training to facilitate independent use of equipment for dressing and grooming.

Orthotics and splints. Both commercial and custom-made orthoses and splints may be recommended or fabricated by the occupational therapist and occupational therapy assistant for people with neurodegenerative disease. These

splints primarily involve the distal joints of the upper and lower extremity, although there may be a need for cervical support (particularly in advanced stages of ALS and PD). (Examples of splints can be found in the original guideline document.)

Modify Occupational Performance

The modification approach in occupational therapy intervention adapts current circumstances to facilitate occupational performance. This is accomplished by modifying the task, the environment, and the individual's approach. In other words, the occupational therapist and occupational therapy assistant find ways to "revise the current context or activity demands to support performance in the natural setting." The compensatory approach does not attempt to restore function to premorbid levels but aims to facilitate optimal engagement at the current level of function. In general, people with neurodegenerative diseases compensate for limitations through education about compensatory strategies and adaptive techniques, use of environmental modifications, and adaptive equipment.

Education. The occupational therapy intervention plan commonly includes education throughout the process, not only for explaining specific techniques, adaptations, and rationale but also for providing current information about the disease process and resources for client, family, and others. (Types of education programs are described in the original guideline document.)

Environmental modifications. The intervention plan may include modifications to the home, community, and work environments of people with neurodegenerative diseases. These modifications are vital to a client whose goals include being able to participate in his or her natural environments. These modifications may be required for several reasons: to allow for wheelchair or scooter access, to ensure a place to rest (most commonly recommended in the work environment), for safety, to reduce confusion or distraction in the presence of perceptual and cognitive difficulties, to minimize distances, and to support the work of a caregiver. Modifications frequently do not require structural changes. Instead, altering furniture arrangement, changing the function of a room, rearranging the location of items, minimizing the use of unsafe floor coverings, modifying lighting, and using devices for cueing may have substantial impact on function and satisfaction.

Adaptive equipment. People with neurodegenerative diseases may use adaptive equipment for several reasons, such as minimizing demands of the activity in the presence of weakness, tremor, ataxia, incoordination, decreased energy, or reduced sensation. (Examples of how adaptive equipment is integrated into a modify/compensation approach to optimize occupational performance are included in the original guideline document.)

Prevention of Deterioration of Occupational Performance

Occupational therapy intervention is designed to provide supports to prevent acceleration in the deterioration of function. Although preventing disease progression is outside the domain of occupational therapy, preventing or slowing deterioration in occupational performance is the unique contribution of occupational therapy intervention. This is achieved through provision of

equipment, support, and education. Empowering the client and family to use and build on strategies already in place will assist in preserving occupational performance of adults with neurodegenerative diseases.

Intervention Review

The third phase in the intervention process is the intervention review. This is a continuous process of reevaluating and reviewing the intervention plan, the effectiveness of its delivery, and the progress toward targeted outcomes. Reevaluation may involve readministering assessments or measurement tools (instruments) used at the time of initial evaluation, a satisfaction questionnaire completed by the client, or questions that evaluate each goal. Reevaluation normally substantiates progress toward goal attainment; indicates any change in functional status; and directs modification to the intervention plan, if necessary. In addition, it also is recommended that one revisit the research evidence if the occupational performance of the client has changed.

Outcomes

Having implemented the intervention process, the outcomes assessment informs decisions related to continuing or modifying the intervention plan, referring the client to other agencies or professionals, discontinuing intervention, and providing follow-up care. If the decision is to continue or modify the intervention, the occupational therapist will return to the intervention process, as previously outlined, and proceed through the planning, implementation, and review of further occupational therapy intervention. If the decision is to refer the client to other agencies or professionals, this may be done in conjunction with or separate from ongoing occupational therapy intervention. Many times, because of the nature of neurodegenerative diseases, a collaborative decision is made to discharge the client but to follow up on a periodic basis.

Discharge

Discharge is initiated at the time when established goals are met or those involved in the provision or receipt of services determine intervention should be discontinued. Although the client may require occupational therapy intervention in the future as a result of the neurodegenerative disease, discharge remains appropriate when goals are satisfied at their current level of function.

For people with neurodegenerative diseases, there may be numerous reasons for discontinuing and reinstating services at a later time, including medical instability (e.g., due to relapse, acute deterioration and loss of function, infection), change in living arrangements (e.g., move from home to care facility), difficulty coping, decreased motivation, or end of life. The reason for discharge should be accurately documented and given appropriate closure.

Follow-up

In the continuum of care, follow-up is often overlooked. However, for people with neurodegenerative diseases, this step is essential given the progressive nature of the conditions and the potential for changing status. Clinics that focus on

neurodegenerative diseases generally have follow-up care built into their administrative processes. For services in which follow-up is at the discretion of the practitioner, it is recommended that follow-up occur 1 to 4 months after discharge. Follow-up can be completed in many ways, including the client returning to the health care setting; the occupational therapist or occupational therapy assistant visiting the client in his or her home (or other relevant environment); or the occupational therapist or occupational therapy assistant contacting the client by telephone, letter, or through a questionnaire.

It must be recognized that occupational therapy services may be required at several points in the life of people with neurodegenerative diseases. Follow-up may be just that place where initiation of further services is indicated, again triggering the occupational therapy process.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence was identified and graded for each condition of interest as follows:

- Multiple sclerosis: 30 articles (Level I: 12, Level II: 8, Level III: 7, Level IV: 3)
- Parkinson's disease: 14 articles (Level I: 8, Level II: 4, Level III: 3, 1 article reports 2 studies)
- Amyotrophic lateral sclerosis: 2 articles (Level IV: 2)
- Transverse myelitis: 0 articles

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

- Assist occupational therapists and occupational therapy assistants in communicating about services to external audiences
- Assist other health care practitioners, case managers, and program administrators in determining whether a referral for occupational therapy services would be appropriate
- Assist third-party payers in determining the medical necessity for occupational therapy
- Assist legislators, third-party payers, and administrators in understanding the professional education, training, and skills of occupational therapists and occupational therapy assistants
- Assist program developers, administrators, legislators, and third-party payers in understanding the scope of occupational therapy services

- Assist program evaluators and policy analysts in this practice area in determining outcome measures for analyzing the effectiveness of occupational therapy intervention
- Assist policy and health care benefit analysts in understanding the appropriateness of determining whether occupational therapy services are appropriate for given populations
- Assist occupational therapy educators in designing appropriate curricula that incorporate the role of occupational therapy for adults with neurodegenerative diseases.

POTENTIAL HARMS

Not stated

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

- This guideline may not include all appropriate methods of care; neither does it recommend any specific method of care. The occupational therapist makes the ultimate judgment regarding the appropriateness of a given procedure in light of a client's circumstances and needs.
- This publication is designed to provide accurate and authoritative information in regard to the subject matter covered. It is sold or distributed with the understanding that the publisher is not engaged in rendering legal, accounting, or other professional service. If legal advice or other expert assistance is required, the services of a competent professional person should be sought.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

An implementation strategy was not provided.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

Living with Illness
Staying Healthy

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

Forwell S. Occupational therapy practice guidelines for adults with neurodegenerative diseases. Bethesda (MD): American Occupational Therapy Association (AOTA); 2006. 75 p. [138 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2006

GUIDELINE DEVELOPER(S)

American Occupational Therapy Association, Inc. - Professional Association

SOURCE(S) OF FUNDING

American Occupational Therapy Association, Inc.

GUIDELINE COMMITTEE

Not stated

COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

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FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

GUIDELINE STATUS

This is the current version of the guideline.

GUIDELINE AVAILABILITY

Electronic copies: Not available at this time.

Print copies: Available for purchase from The American Occupational Therapy Association (AOTA), Inc., 4720 Montgomery Lane, Bethesda, MD 20814, Phone:1-877-404-AOTA (2682), TDD: 800-377-8555, Fax: 301-652-7711. This guideline can also be ordered online at the AOTA Web site.

AVAILABILITY OF COMPANION DOCUMENTS

The following is available:

- Occupational therapy practice framework: domain and process. 2002. American Journal of Occupational Therapy, 56, 609–39. Electronic copies: Available to subscribers from the American Journal of Occupational Therapy Web site.

PATIENT RESOURCES

None available

NGC STATUS

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